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# PARTICIPATION IN COMMUNICATION AND DECISIONS WITH REGARDS TO NURSING CARE: THE ROLE OF CHILDREN

Siew Pien Lee (Lee SP) PhD<sup>a</sup>, Elaine Haycock-Stuart (Haycock-Stuart E) PhD<sup>b</sup>, Kay Tisdall (Tisdall K) PhD<sup>c</sup>

<sup>a</sup>. Department of Special Care Nursing, Faculty of Nursing, International Islamic University Malaysia, Kuantan, Pahang, Malaysia.

<sup>b</sup>. School of Health in Social Science, The University of Edinburgh, Scotland, United Kingdom.

<sup>c</sup>. School of Social and Political Science, The University of Edinburgh, Scotland, United Kingdom.

Corresponding author: [siewpien@iium.edu.my](mailto:siewpien@iium.edu.my)

## Abstract

**Objective:** The study was to examine the role of children in communication and decisions regarding their nursing care in a paediatric oncology ward in Malaysia.

**Methods:** The principles of focused ethnography underpinned the study design. Fieldwork took place over six months in one 32-bedded paediatric oncology ward. Twenty-one children, ranging in ages from 7 to 12 years diagnosed with leukaemia, their parents and 19 nurses participated. Data collection consisted of participant observation and semi-structured interview.

**Results:** Hospitalized children employed different roles of passive or active participants during the communication and decisions about their nursing care. Importantly, children are more likely to become active participants in the communication process when nurses interact directly with them, listening to them and giving them opportunities to ask questions in either the presence or absence of their parents. Equally, children are likely to be more passive participants when nurses do not communicate directly with them, choosing instead to directly interact with the child's parents. This study highlighted that the role of children as active and passive participants is not permanently engaged by individual children, rather their role fluctuates throughout the hospitalization journey. The fluctuations of a child's role are highly dependent on their preferences: how and when they want to be included in the communication and decisions process. Children's roles in communication and decisions are also varied and dependent on their particular contexts. A child's participation in one situation does not consistently reflect their participation with their role in other situations. The ways in which the children participate were oscillated throughout their hospitalization.

**Conclusions:** This study provides empirical insight into children's experiences of triadic (child-nurse-parent) interaction during the decisions about their nursing care in paediatric oncological setting. A key recommendation calls for the development of assessment strategies to determine the 'ideal' position children would like to occupy, at any given point in time, throughout their hospitalization.

**Keywords:** Children's role, participation, communication, decision-making, nursing care, Malaysia.

## Introduction

There is a growing recognition that in general children should be involved in decisions that concern them. The existing evidence suggests that there is more scope and opportunities to further involve children in decisions that affect them when they are able to participate and that children would like to be active participants in their health care, or at least have the choice to participate (3). It is generally acknowledged that children's participation in consultation and decisions are essential for adherence and improving quality of nursing care to the children (2). Yet, the involvement of children in the decisions is frequently being ignored by the healthcare professionals (5). This may be a result of children's own choice, but it may also be caused by adults' protectiveness or incomplete knowledge of children's ability to understand information and to be an active participant in decisions regarding their care (13). Some children have reported being dissatisfied with their non-participant status and that this can hinder their ability to understand their illness and wish to have their expressions about care considered (5).

The research highlights particular areas of participation of children in the decisions-making process. These areas include the role of children in decisions has been marginalized (16). However, there is little research on the role of children in decisions regarding their care by observing the child-nurse-parent triadic interaction during the nursing care provision, and this may minimize the understanding of the whole picture of the child in decisions with regards to their nursing care. The necessity for an evidence base on the role of the child in health care decisions is explicitly emphasized in several studies exploring the nature of communication for hospitalized children (12, 13), and children experiences of participation in decisions relating to health care (3, 5, 16). One dominant theme to emerge from these studies as a major concern for children of all ages was that children's role in the child-nurse-parent triadic interaction is rarely acknowledged. This is an area that requires further investigation owing to the significant lack of research addressing the role of children in the communication and decisions about their nursing care in paediatric oncological setting.

## Methods

The principles of focused ethnography underpinned the study design. The design incorporated participant observation and interview with children, their parents and nurses. In this particular study the first author spends a total of six months over 2014 – 2015, as participant observer, observer and obtained data from children (n = 21) aged 7 – 12 years, their parents (n=21) and nurses (n=19) in a 32-bedded paediatric oncology ward in one of the public hospitals in Malaysia. The ward was selected because it catered for a wide age range of children with leukaemia. Child participants were purposively selected on the basis that they met the study's inclusion criteria: (1) they were diagnosed with leukaemia; (2) they were aged between 7 –12 years; (3) they were able and willing to take part and (4) they had parental consent. Children younger than seven years and those in critical condition were excluded. Parent participants were the parent of the child participants, and nurse participant were purposively selected on the basis that they provide direct nursing care to the child participants.

Fieldwork was conducted for six months over 2014 – 2015. During this period, non-continuous participant observations were conducted and were spread out throughout the fieldwork (8). Observation took place three days per week (alternate days). In her participant observer role, the first author (a nurse) was not part of the ward team, whenever appropriate she participated in non-legally defined roles as might be performed by a care assistant, such as talked and played with the children, helped with the meals, accompanied the children to various parts of the hospital (such as the radiology department, and clinics), and assisted with the nursing procedure (dressing, blood taking, vital signs checking). She did not perform any activities that are part of the legally defined role of the nurse (e.g. giving medication and administration of treatments) to the children.

The semi structured interviews were recorded using an audio recording device with participants' consent. Each interview lasted from 30 to 90 minutes depending on how much time the participants had

and how much they had to say on each topic area, however, interviews with children lasted no more than 60 minutes. All interviews were transcribed verbatim to facilitate an analysis of what the interviewees said and how they said it (8). Using the focused ethnographic data analysis techniques, fieldnote and participants' statement were examined for meaning and similar statements coded (15). The codes adhered closely to participants' own action and accounts. The codes were then grouped into key themes.

## Results

### *Child as passive participant*

The role of the child as passive participant is conceptualized the situation where the children being overshadowed by their parent or nurses and were least visible within the decisions process.

#### *Scenario 1*

*Alexis, 11 years, diagnosed with chronic lymphoblastic leukaemia, was admitted for chemotherapy. He was under the care of Alma (the nurse). At his unit, Alexis is sitting on the bed watching TV. Alma (the nurse) comes in and informs his parent, Jenny, that they must transfer to a single room because Alexis is suspected of having an eye infection. Alexis appears distracted by the conversation between Alma and his parent. He stops watching TV and turns to Alma but does not say any words. He seems interested and continues listening to the conversation. Jenny asked, "How long do we have to be in that room?" Alma answered, "Until the blood culture result is normal, then you will be transferred back to the shared room." Jenny smiles and says, "Hopefully not long, I don't like the room because it feels isolated, no friends to chat with." Without a verbal response, Alexis continues observing the conversation between his parent and Alma. Neither Alma nor Jenny involved Alexis in the discussion.*

The above scenario serves to illustrate that the nurse, Alma relayed the information to Jenny instead of Alexis. Although Alexis appeared to be conscious and alert, behaviour associated with receptivity to information, he was not addressed directly by Alma; rather the nurse and his parent conversed about him in his presence. Alexis was visible within the communication process, but the nurse and his parent were essentially ignoring him. He sat mutely in the background within the communication process.

The role of children as passive participant is often viewed as negative and inhibitive to the quality of communication and care (13). Nevertheless, some of the children were not regarded as passive participants in the communication process in terms of being prevented from participating, and rather they took on this role willingly:

*I don't mind, I usually hear what they discussed. I knew it. Even if I don't know, my mum will definitely tell me later on. So, it's okay if nurses do not tell me... and... if I want to know something, I can just ask them... (Emelda, 12 years)*

Emelda appears to be satisfied with her role as passive participant at a particular point in time. Her explanation indicated that she was not bothered about getting direct information from healthcare professionals. In fact, what is important for her is that the information still reaches her via her parent or by simply overhearing the nurse communicating with her parent. Emelda noted that if she wanted more information, he could simply ask the nurses, indicating children may have their own preferences about how and when to be included in the communication process.

### ***Child as active participant***

The role of the child as active participant conceptualizes the situation where the children were most visible within the communication and decisions process. In this situation, children were able to voice out their wishes in the communication process.

#### ***Scenario 2***

*Alexis, 11 years, has a severe mouth ulcer and experiences severe pain. Ann, the nurse in-charge of him, comes in to his unit to commence an IV Morphine infusion for him. Ann told Alexis that she is going to start the medication to ease the pain. However, Jenny (the mother) told the nurse to give the medication after her child takes his breakfast. Alexis appeared in pain and informed the nurse to give the medication straightaway, with the hope that he can eat peacefully after the medication is infused. Jenny, without any objection, just smiles and looks at her son. Ann, without delaying start the infusion as requested by Alexis.*

In contrast to the previous observation, in this situation, Ann (the nurse) was directly communicating with Alexis by informing him of what was going to be happen to him. However, it appeared that this was largely focused on the nurse's accomplishment of her routine tasks, and not specifically tailored to Alexis's agenda. When the nurse attempted to communicate with Alexis, the parent interposed not only to answer for him, but also to voice her own preferences to have the procedure after her son had eaten his breakfast. Alexis appeared to have opportunity to express his preferences to have the pain medication immediately. Alexis was also afforded with an opportunity to voice out his needs. This allowed Alexis to address his own agenda.

The opportunity being offered by the adults (parents and nurses) to children, would allow children to be active participant and able to make their own decisions according to their needs:

#### ***Scenario 3***

*Albert, 8-year-old boy is under the care of Bella (the nurse). Albert is on nasogastric tube (a narrow bore tube passed into the stomach via the nose) because he refuses oral medicine. In this case, the tube is mainly for the purpose of giving oral medication. He is scheduled for the change of RT. During the removal of the tube, Albert appears calm, he follows Bella's instruction to breath in and out, and he does not struggle or cry. The tube was successfully removed without difficulty. When Bella prepares to reinsert the new tube, Albert starts to cry, and he refuses the reinsertion. He pushes Bella's hand away. Bella, with a firm voice, says: "If you are willing to take your medication orally, I will not insert the new tube." Albert continues crying. Bella repeatedly tells Albert that the RT will not be inserted if he is willing to take his medication by mouth. A bit later, suddenly Albert in a crying tone says: "I will take the medication by mouth." Albert promises to take the medication by mouth. Finally, Bella decides not to reinsert the tube and gives Albert time to take his medication. Before leaving, Bella reminds Albert that she will come back to check if he has taken his medication.*

In this scenario, it can be seen that whenever the opportunities were given to the children, they would take the opportunity. Initially, Bella is explaining about the reinsertion of the tube to Albert and his mother. Reassurance was given when she announces that Albert does not need the tube which can be unpleasant for him, if he is willing to take medication orally. Finally, she appears to be listening to Albert when she makes a decision that accommodates his request, which is conditional on his choice and action (to take the medication). Although Bella appeared to exert her power towards Albert by using a strong tone of voice, she seems to be trying to negotiate with Albert when she spends time carrying on a dialogue with him and not hurrying the procedure. Bella appears to recognize Albert as a valid

partner in his care, whose opinions and wishes were taken into consideration. In addition, the flexibility of Bella in negotiating the nursing care appears to motivate Albert to make his own choice, which ultimately resulted in gaining the child's cooperation and acceptance of care (3), although Bella's concern could mainly be related to promoting the compliance of the child with treatment. Despite Bella using threatening behavior towards Albert (using a high tone of voice), the interpersonal skills used by Bella when she is negotiating with Albert, influence the degrees to which Albert participates in the decisions. In other words, Albert received information about the need of the insertion of RT. This would mean that there was a two-way communication taking place where the nurse carried on a dialogue to negotiate with him, and finally, the nurse made the decision according to his wish.

## **Discussion**

As illustrated through the first two scenarios, the same child can have different roles in the decisions and communication process throughout the period of hospitalization. Essentially children were passive and active participants. The passive participant represented times when children were least visible and position in the background within the decision-making process (as illustrated in scenario 1). This finding concurs with previous studies which reported that health consultations mostly involve parent and health care professionals and children largely being marginalized (6, 20). Furthermore, this finding also lends to support other studies exploring the nature of communication for hospitalized children, which suggested that children often stood in the background of the communication process because the flow of the conversation was predominantly directed towards their parents (12). Contrastingly, the active participant represented times when children were most visible within the decisions process (as illustrated in scenario 2 and 3). This role of children also coincides with prior studies, investigating the children's experiences of communication in an inpatient hospital setting, which reported that some children were the focal point of the communication process, holding a leading position, with the health professional communicating directly with them, or simultaneous with them and their parents (12, 16). The child's increased participation was partly as a result of the health care professionals allocating the child more space within the consultation and also partly because of the child taking more initiative (12). This has parallels with findings from this study.

Notwithstanding this, nevertheless, there were children appeared to be satisfied with their role as passive participant. This suggests that although being excluded from the discussion and employing a passive participant role, a child is satisfied because he desires such a role (13). This is contrary to studies reporting that some children were dissatisfied with their non-participant status in the communication process, which hampers their ability to make sense of their illness and to have their interests considered (14, 20). In this study, some children noted that if he wanted more information, he could simply ask the nurses, indicating children may have their own preferences about how and when to be included in the communication process. This finding supports the need for each child to explicitly decide upon how and what information they want to receive (22), because they might have differing preferences at that time (16). For instance, in certain situations, they might want to be an active participant whilst at other times and in other contexts be a passive participant. It became evident that the children in the communication process are highly influenced by their desire for information. For example, when the child desires more information, may take an active role in the communication process by asking for the desired information. Whereas, he might remain unresponsive when he feels he has had enough information.

### ***Oscillation of the roles***

Situation 2 illustrated that in the beginning Alexis appeared to employ a position as passive participant when his parent tried to interrupt the conversation; however, from this point he was an active participant, when he voiced his preferences for the infusion to commence immediately. In contrast to the previous scenario, Alexis had a stronger wish to be involved in the conversation when he personally requested pain medication. His response, therefore, may suggest that he was too sore and just wanted the pain to

go away, indicating he knows better how he feels. This supports the findings that the physical state of the child could influence their role in communication and decisions (3). The situation of Alexis also supports the argument that the decisions made by parents may not necessarily be what children want and may not be in their best interests (4). Alexis appears to know his pain threshold better than his parent when he stated that he needed the infusion urgently at that time, and thus, takes on the active participant role. Although the majority of nurses in this study might agree that parents have a better understanding compared to children, and know best regarding their child, this example; however, has shown that this is not always the case, highlighting the need for nurses to examine the individuality of each with regard to their care needs.

As emerged in this study, not all children necessarily acted as passive participant role, standing in the background and overshadowed by their parents at all times. At some particular times and for some particular situations, children were observed to occupying an active participant role. As illustrated in the both examples, Alexis eagerly voiced out his wish to have the pain medication because he was acutely in pain and wanted to get rid of his pain, although previously he appeared to be comfortable with his passive participant role. Alexis did not seem to fully occupy a position as active participant or passive observer within the decision-making process, but his position was constantly changing throughout his hospitalization, oscillating between active participant and passive observer.

This ties in with what Lambert and colleague (13) concluded, namely that children did not exclusively occupy a forefront or background position within the communication process; rather they oscillated along the continuum between the two extreme poles of 'being overshadowed' (in this case as passive participant) and 'being at the forefront' (as active participant). The fluctuation of the role of the child in the interaction could be partly because of the nurse allocating the child opportunities and space within the communication, or partly because of the child taking more initiative. In the second situation, Alexis, for example, although the parent interrupted and blocked his interaction with the nurse, when he eagerly tells his preferences to get things done, the nurse stays focused on him, thus his active role was evidenced. It can be seen that, when children suddenly change their role from passive to active role, the role of other members in the triad were affected (9). For instance, when Alexis became an active participant, his parent become a passive one in the background. The nurse, however, remained in the position to decide whether to follow the preference of the parent or that of the child, demonstrating the role of nurses in affecting the child's role in the communication and decisions.

## **Conclusion**

This focused ethnographic study investigated the role of children in decision-making. The findings of this study concurred with previous literature that hospitalized children employed different roles of passive or active participants during the decision-making process with nurses and parents about their own nursing care. Importantly, children are more likely to become active participants in the communication process when nurses interact directly with them, listening to them and giving them opportunities to ask questions in either the presence or absence of their parents. Equally, children are likely to be more passive participants when nurses do not communicate directly with them, choosing instead to directly interact with the child's parents. This study highlighted that the role of children as active and passive participants is not permanently engaged by individual children, rather their role fluctuates throughout the hospitalization journey. The fluctuations of a child's role are highly dependent on their preferences: how and when they want to be included in communication and decisions process. Children's roles in decisions are also varied and dependent on their particular contexts. A child's participation in one situation does not consistently reflect their participation with their role in other situations. The ways in which the children participate were oscillate throughout their hospitalization. There is a need to support the child to better enable him or her to become a partner in communication process. This study highlights the need for all health professionals to embrace the individualism of each child patient with regard to their specific needs.

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**Conflict of interest**

The authors declare that there is no conflict of interest regarding the publication of this article.



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